[COMMITTEE PRINT]

# FINANCING CARE FOR PATIENTS WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

## A BRIEFING

BY THE

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

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## STATEMENT OF CONGRESSMAN MARIO BIAGGI

As the Chairman of the Subcommittee on Human Services of the Select Committee on Aging, I am pleased to present the following committee print based on the excellent work of Dr. Karen Davis and Ms. Patricia Neumann of Johns Hopkins University. This print is the outgrowth of a one-day workshop held in May, 1986 and sponsored by seven Representatives and ten Senators, all of whom were united in their concern about financing long-term care for those who suffer from Alzheimer's and related dementias.

I want to give special thanks to the ranking minority member on the Subcommittee, Congresswoman Olympia Snowe. It was she who first conceived the idea of a workshop on this topic and it was through her efforts that the workshop and this print became reality. Ms. Snowe has been a leader in legislating on behalf of victims of Alzheimer's disease and their families. Indeed, I was proud to join with Ms. Snowe in developing legislation which, for the first time, would provide funding for services in the Older Americans Act for families of Alzheimer's victims.

This workshop represented a rare opportunity to bring together experts in the fields of Alzheimer's disease and health financing in order to begin a dialog on ways in which to address the financing of long-term care for this special population. The first version of this paper was written expressly for the workshop, to be used as the basis for discussion. Participants generated comments and criticisms that were incorporated into the revised version which forms the substance of this print. The participants brought a high level of expertise to the subject in an effort to forge new ground and lay a basis for further discussion. It is my judgement that they were able to achieve both goals.

While we are all aware that the problems for those who must deal with the long-term care system are obvious and numerous, the solutions have been remarkably elusive. This committee print intentionally lays out a broad range of policy options. No effort is made to choose one mechanism for change over the other. The intent was and is to generate ideas, and I believe we have succeeded.

It is my hope that this document will serve as a useful tool as we move forward in the discussion of the financing of long-term care for those with Alzheimer's disease and related dementias.

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## STATEMENT OF CONGRESSWOMAN OLYMPIA J. SNOWE

On May 19, I sponsored, along with Mr. Biaggi, Mr. Stark, Mr. Madigan, Mr. Roybal, and Mr. Conte a workshop aimed at better understanding the mechanisms available for financing long-term care for those who suffer from Alzheimer's disease. That day-long workshop focused on a paper that was written by Dr. Karen Davis and Ms. Patricia Neuman of Johns Hopkins University, entitled "Financing Care for Patients with Alzheimer's Disease and Related Disorders". The text of the following committee print is a revised version of that paper, edited to represent the comments of the participants who were present during that workshop.

The unique contribution of that workshop is that it was the first time that discussions of the financing of long-term care had been aimed specifically at the Alzheimer's population. Dr. Davis and Ms. Neuman provided us with a range of options, some controversial, some less so; some achievable within the current framework of health care systems, some requiring more extensive revisions. At a minimum, this committee print is intended to stimulate discussion and to create an environment in which we can positively review the steps that we can take in order to address the problem of financing the care of those who suffer from dementia.

In some ways, Alzheimer's and the related dementias represent a unique challenge to the health care system. Those who suffer from Alzheimer's disease can range in age from individuals in their 40's to those of quite advanced age. As a consequence, eligibility for many of the kinds of services that are needed may not be available for some Alzheimer's victims. Victims may suffer from the disease for anywhere from 3 to 20 years and may outlive their own financial resources and those of their family. It has been estimated that families with Alzheimer's disease victims will incur costs that range from $17,000 to $50,000 per year. As a consequence, as we think of the financing of long-term care, we should think of it as it assists not only the victim, but also the family that is interested in and involved with the care of that person.

It is my hope that as we approach the 100th Congress, we can look forward to progress in the diagnosis, treatment, and care of those who suffer from Alzheimer's disease. It is my hope, further, that those of us who are able to participate in this historic Congress will be able to address legislatively some of the crucial problems that face our constituents, our friends, and our family members as they struggle to come to grips with this devastating illness.

I want to thank Congressman Biaggi, the Chairman of the Subcommittee on Human Services of the Select Committee on Aging, for his continuing support for efforts to bring education and legislation to the public on Alzheimer's disease. His support of this committee print has made it possible. Further, I want to thank the Office of Technology Assessment for assisting me in organizing the workshop on "Financing Long-Term Care for Alzheimer's Disease and Related Disorders" and the Alzheimer's Disease and Related Disorders Association who underwrote some of the costs of that workshop.

I believe we can take great satisfaction in the fact that we have forged new territory with this print. I consider it a provocative document which should provide direction to the future debate on financing long-term care for Alzheimer's disease.

EDWARD R. ROYBAL, CALIFORNIA
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## STATEMENT OF EDWARD R. ROYBAL
## CHAIRMAN, HOUSE SELECT COMMITTEE ON AGING

Today in America, more than two million people suffer from Alzheimer's disease and related disorders. Added to their suffering are millions of family members who face the emotional and financial burden of their care on a daily basis.

**As tragic as Alzheimer's disease is, it is but one, devastating example of catastrophic illness for which the vast majority of Americans have no financial protection.** Catastrophic illness can strike any of us. With few exceptions, the impact of the illness creates a second catastrophe -- a financial catastrophe. Few Americans are immune from the financial risk of short and long term catastrophic illnesses. Its reach extends further into higher income levels than most of us care to realize.

Where this country takes pride in the contributions that have been made to modern medicine, it can only feel shame in its failure to adequately protect millions of Americans from the devastating costs of catastrophic illnesses such as Alzheimer's disease. It is a deplorable fact that the United States stands out as one of only two countries in the world (the other being South Africa) that has yet to develop some form of national health plan.

The time to act is now. For this reason, the authors of this report are commended for their timely work. **As we consider their and other options for financing catastrophic care, the merits of each should be tested against one critical criterion -- the equal right of all Americans to affordable, high quality care.** In this spirit, I have introduced a national health plan, "USHealth," that provides comprehensive health coverage for Americans of all ages and incomes at a cost the nation can and must afford. On behalf of the over 31 million uninsured and over 200 million underinsured Americans, we must move swiftly and reach a consensus -- not on whether they will be protected, but how.

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September 11, 1986

Honorable Mario Biaggi, Chairman
Honorable Olympia J. Snowe
Subcommittee on Human Services
U.S. House of Representatives
Room A716, House Annex #1
Washington, D.C. 20515

Dear Representatives Biaggi and Snowe:

In 1906, a German neurologist named Dr. Alois Alzheimer first identified the unique brain abnormalities that were to become the hallmark of the disease that now bears his name. Since that time, our Nation has built an impressive health record. But unfortunately, while tremendous strides have been made in the fields of science and medicine, the cause of Alzheimer's disease still eludes us.

From the time it was first organized, the Alzheimer's Disease and Related Disorders Association (ADRDA) has worked to ease the burden that this illness places on the families of its more than 2.5 million victims. Apart from promoting greater public awareness and expanded medical research, ADRDA has sought to call attention to the enormous physical, emotional, and financial hardships now being borne by families of Alzheimer's victims.

As evidenced by the workshop discussed in this report, relatively little is available to help meet the long-term care needs of victims and their families. In fact, a recurring theme in the history of each family's problems is the difficulty experienced in finding both the medical and social resources required for the diagnosis, management, and care of the patient.

Our hope is that this report, issued on the 80th anniversary of Dr. Alzheimer's discovery, will lay the groundwork for a new challenge in the form of a responsive services research and development strategy.

I wish to commend those Members of Congress who supported this effort, as well as the staff of the Office of Technology Assessment who dedicated so much time and energy to making it a success.

Sincerely,

Jerome H. Stone

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The Honorable Edward R. Madigan

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# FINANCING CARE FOR PATIENTS WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

Karen Davis and Patricia Neuman

Alzheimer's disease and other forms of dementia inflict an enormous financial and emotional burden on patients and their families. The cause of Alzheimer's is not known, and no treatment is effective in stopping its relentless progression. Dementia can be totally devastating to close family members, causing the loss of the human quality of cognition and reducing the patient to total dependence on others.

Current programs to finance health care do little to lessen the financial burden of caring for such patients. Since the prevalence of the disease increases with age, the majority of Alzheimer's patients are age 65 or over and covered by Medicare. Medicare pays hospital, physician, and laboratory services required for the diagnosis or management of Alzheimer's patients -- but excludes the services that are required to provide or assist with everyday care. Prescription drugs, respite services, attendant care, personal care, adult day center care, and nursing home care are for the most part not covered by Medicare. Private health insurance similarly largely excludes such services. Medicaid does cover nursing home care for impoverished patients, and in some states other services in the home and community. Families have a choice of being emotionally bankrupt by

providing all needed care directly or financially devastated by paying others for the care.

This paper sets forth a series of policy options that could reduce the financial strains on those families unfortunate enough to be struck by this devastating disease. These policy options range from modest changes in current governmental programs to more comprehensive solutions. Options also include incentives that government can provide to encourage family and voluntary efforts. Serious consideration of these options is urgent given the extent of the financial burdens, absence of current support, and loss of human dignity that Alzheimer's disease and other forms of dementia inflict.

## I. Current Financing for Patients with Alzheimer's Disease

Assessment of the cost and sources of financing care for patients with Alzheimer's disease and related disorders is very inadequate. Accurate counts of the number of individuals with Alzheimer's are difficult to obtain. Estimates of the cost of providing adequate care are even less firm. Yet, concern about the potential budgetary impact of policy initiatives to provide assistance to Alzheimer's patients and their families is a major barrier to action. Continuing efforts to obtain more precise estimates of prevalence of Alzheimer's patients by degree of impairment, sources and

extent of informal (unpaid) support, utilization of health and long-term care services, cost of providing health and long-term care services, and distribution of expenditures by type of patient, type of service, and source of financing should all be important elements of future research efforts.

A. Prevalence of Alzheimer's Disease

Definitive diagnosis of Alzheimer's disease at present can only be made by histologic confirmation obtained through performance of a cerebral biopsy or an autopsy. The ability to diagnose Alzheimer's clinically, however, has improved to at least a 90 percent assurance of accuracy through physical, psychiatric, and neurologic examinations, mental status testing, history taking, and laboratory tests including CT scan. (Ron et al., 1979) While this level of accuracy is technically feasible, few providers are trained in the latest methods, and many families do not receive clear cut confirmation.

Hope for new and better diagnostic methods has recently surfaced with the research finding that a protein has been found in the brains of 28 Alzheimer patients that is missing in normal brains. (Wolozin et al., 1986) This protein, labelled ALZ-50 antigen, may prove to be an effective screening tool -- particularly if it can be detected in the spinal fluid.

Best estimates indicate that about 2 million Americans currently have Alzheimer's disease. (Katzman, 1986) These

include those with severe dementia (perhaps 700,000 individuals) and those with mild to moderate dementia. Alzheimer's patients represent about 55 percent of all patients with dementia or 2 million out of a total of 3.6 million patients with dementia. Other causes of dementia include vascular disease including multi-infarct causes of dementia (about 10 to 20 percent of cases), neurodegenerative disorders, and other causes.

Alzheimer's disease is diagnosed, in part, by ruling out other causes of dementia. The Department of Health and Human Services Task Force on Alzheimer's Disease concludes that a diagnosis of probable Alzheimer's disease requires the presence of dementia "established by clinical examination and documented by the Mini-Mental Test, Blessed Dementia Scale, or similar examination ... with evidence of deficits in two or more areas of cognition, progressive worsening of memory and other cognitive functions; no disturbance of consciousness ... absence of systemic disorders or other brain diseases that in and of themselves could account for the ... deficits." (McKhann et al., 1984)

Given the enormous care requirements of a patient with severe dementia of either the Alzheimer's or other types, dementia is a major cause of nursing home admission. One study estimated that 65 percent of nursing home residents met the clinical and mental-status criteria for dementia, and approximately 55 percent of deceased nursing home patients

were found to have had Alzheimer's disease. (Katzman, 1986) If these estimates are applied to the entire nursing home population, approximately 0.7 to 1.0 million of the 1.5 million patients in nursing homes have Alzheimer's disease.

B. Care Requirements of Alzheimer's Patients

The types of health and long-term care services required by Alzheimer's patients depends upon the stage of progression of the disease (e.g. mild, moderate, severe dementia), the manifestations of the disease (e.g. irritability, agitation, depression, sleep disorders, incontinence, verbal and physical aggression), the presence or absence of caregivers in the home to provide assistance (e.g. supervision, personal care, administration of medications), and numerous other factors.

At the risk of considerable oversimplification, Alzheimer's patients and their families require the following types of services:

- Diagnosis of the disease -- physician visit(s) to take history, conduct physical, psychiatric, and neurologic examinations, formal mental health testing, and laboratory tests including CT scan.
- Management of the disease -- ongoing physician visits to monitor progress of disease, provide counseling, prescribe drugs for symptomatic treatment to help maintain the patient's socialization and ability of the patient to remain within

his or her family or social situation.

- Acute care -- hospital, physician, and other health and mental health care services required to treat any related or unrelated physical problems.
- Home or community based services -- adult day care centers, attendant care, or personal care to assist family members in their care of the Alzheimer's patient.
- Information and support -- hot lines, information clearinghouses, and self-help groups to provide educational and psychological support to caregivers.
- Respite services -- relief for caregivers for certain hours during the day or week, or vacations.
- Nursing home care for patients with severe dementia or behavioral disturbances for whom families are unable to provide care or for patients without able caregivers in the home.

C. Cost of Caring for the Demented Elderly

Two recent studies provide estimates of the prevalence of dementia among the elderly and the costs of caring for these individuals. (Hu, Huang, and Cartwright, 1986; Huang, Hu, and Cartwright, 1985) The studies included patients with all forms of dementia including multi-infarct dementia, but exclude patients under age 65.

The first study was based on a sample of 25 nursing home patients and 19 elderly living in their own homes. (Hu, Huang, and Cartwright, 1986) Nursing staff and family members maintained diaries of time spent in caring for the patient. Costs were for nursing home and home care services, but did not include hospital care, drugs, and physician services. The average annual cost of caring for dementia patients in the nursing home was $22,458 in 1983, with nursing staff spending 36 percent more time on the care of a demented patient than for other patients. The average annual cost of caring in the home was $14,815 for severe dementia patients and $6,515 for mild and moderate cases of dementia.

In another study, estimates were made of the total economic cost of dementia among the elderly in the U.S. in 1983. (Huang, Hu, and Cartwright, 1985) They estimated that a total of 4.1 million elderly suffered from dementia in 1983. Of these, 795,000 were in nursing homes, 1.1 million were severely demented and in the home, and the remaining 2.2 suffered from mild to moderate dementia and were at home. They estimated that the total medical care costs of caring for these patients was $8 billion in 1983, including hospital care, nursing home care, physician services, drugs, and other medical care services. Informal home care services were valued at $26.7 billion (primarily the imputed value of time spent by family members, relatives, and friends), and formal care services from social service agencies at $1.1 billion.

Indirect costs such as the loss of life value through disability and early death were valued at $39 billion.

D. Current Financing Programs

Medicare and Medicaid are the major current public sources of financing for the care of Alzheimer's patients. Medicare covers most persons age 65 and over and those who have been permanently and totally disabled for two years or more.

Patients with Alzheimer's disease under age 65, however, may have considerable difficulty qualifying as disabled persons since eligibility is linked to Social Security Disability Insurance (SSDI) which offers minimal recourse to persons with various forms of dementia. SSDI is designed to provide working-age individuals who are permanently physically or mentally disabled with cash benefits. Eligibility for SSDI is difficult to obtain. It is granted if the applicant can demonstrate either that the condition and its level of severity is included in the "Listing of Impairments" or that the disabling condition precludes substantial gainful activity for a prolonged period of time. Alzheimer's is not listed as a disabling impairment. This places the entire burden of proof upon the applicant to demonstrate his or her inability to work. And, if SSDI eligibility is determined, applicants must wait 5 full months before receiving cash benefits, and another 24 months before becoming eligible for Medicare.

Medicare covers hospital, physician, laboratory, and other services. Psychotherapy services are covered up to a limit of $250 per year. Home health services are covered without co-payments, but only under restrictive circumstances. Medicare's home health benefit is designed to exclude ongoing personal or attendant care; patients with a chronic, progressive disease like Alzheimer's typically do not even qualify for skilled home care services. Nursing home benefits under Medicare similarly do not apply to custodial care required for Alzheimer's patients. The average length of a covered stay under Medicare is only 30 days. (HCFA, 1985) This is a relatively insignificant benefit for the dementia patient with an ongoing need for care.

Medicaid covers those low-income persons meeting certain categorical restrictions (e.g. aged, disabled) and state income and asset standards. Its restrictive eligibility conditions preclude coverage of most Alzheimer's patients until progression of the disease requires placement in a nursing home and most financial resources of the patient are exhausted. It also reduces a spouse to poverty subsistence before Medicaid nursing home benefits apply.

Medicaid does provide intermediate care and skilled nursing home benefits. States may apply for a waiver to cover a wider array of home and community-based services if the cost of providing such services will be offset by savings

from reduced nursing home use. As of July 1983, 45 waivers from 35 states had been approved. (Lave, 1985) No information is reported on how many individuals covered under waivers have Alzheimer's disease or related disorders. Many states have restricted the waivers to certain categories such as the mentally retarded or elderly. Relaxing the cost neutral provision would be required to provide much assistance to care for Alzheimer's patients.

Private health insurance coverage for services needed by persons with dementia is virtually nonexistent. MediGap insurance policies that supplement Medicare rarely cover either home health services or any nursing home days. (Rice, 1986) Recently private insurance companies have moved tentatively into offering limited nursing home coverage. These policies place strict limits on daily payments and length of maximum coverage (e.g. three years). Marketing efforts are targeted on attracting higher income, younger, and healthier individuals. Because of a concern with adverse selection and induced demand, companies charge high premiums with considerable loading. Many elderly incorrectly assume that Medicare covers nursing home care. Even when informed, older people have not responded to outreach efforts to enroll them in private long-term care plans. Insurance companies, on their part, are reluctant to offer home care and other custodial services most desired by families and patients.

E. Gaps and Inadequacies in Current Programs

Current programs, as important as they are, fail to meet the major needs of Alzheimer's patients. Major problems with current coverage include:

- Medicare does not cover all Alzheimer's patients -- especially those under age 65.
- Medicare's benefit package is not broad enough to cover the major health and long-term care services required by Alzheimer's patients.
- Medicaid is available only to those who are impoverished.
- Medicaid benefits, while broader than Medicare's, do not typically provide everyday care services in the home or respite services.

Current financing programs do not relieve the enormous emotional and financial burdens on Alzheimer's patients and their families. Elderly individuals living alone without children (about 25 percent of the 8 million elderly who live alone do not have children) are especially vulnerable to nursing home placement if they have Alzheimer's disease.

Private health insurance does little to remedy this situation. Because the disease destroys the ability of patients to care for themselves, the primary need is for supervision and personal care. Even in cases where family members are available to provide such services, the burdens of a "36-Hour Day" (Mace and Rabins, 1981) destroy the personal lives of caregivers and often lead to nursing home

placement. About 72 percent of functionally disabled individuals residing in the community rely exclusively on family and friends for long-term care assistance. (Doty, 1984) Some long-term care providers, such as adult day centers, are unwilling to accept Alzheimer's patients. Financing of respite services and other services in the home and community to assist and give periodic relief to caregivers and nursing home care for Alzheimer's patients are top priorities for improvements.

## II. Policy Options

The major decision facing any policy initiative to improve financing care is whether to restrict this initiative to Alzheimer's patients alone. A case can be made that dementia poses much more extraordinary burdens than other types of health problems requiring long-term care and is worthy of special attention. Many would question, however, the equity of improving coverage for patients with Alzheimer's disease, but not covering multi-infarct dementia, for example, that creates many of the same emotional and financial burdens. One strategy might be to cover Alzheimer's disease and related disorders including other forms of moderate to severe dementia. Another alternative would be to improve financing of long-term care for all patients meeting certain functional impairment criteria.

For the purposes of this paper, options will be set forth that address specifically the needs of Alzheimer's patients although the same approach, in many cases, could be extended to either all patients with dementia or all patients in need of long-term care.

Since Medicare and Medicaid are the major current sources of financing for health and long-term care services of Alzheimer's patients, several options focus on improvements in these programs. Other options provide targeted funds through new categorical programs. Finally, options to provide incentives for family and voluntary efforts are considered.

At this time it is not possible to provide careful cost estimates for these options. Such estimates would need to be developed for serious consideration of the options to proceed. After finalization of a desirable range of options, cost estimates might be requested from the Congressional Budget Office, the Health Care Financing Administration, or private organizations with long-term care financing cost modeling capabilities.

A. Incremental Improvements in Medicare

One approach would be to expand eligibility and benefits under Medicare to Alzheimer's patients. This option would not provide direct financing for nursing home care but would improve coverage for other services required by Alzheimer's patients.

1. Option 1: Medicare Expansion

The components of this option include:

- Expansion of Medicare eligibility to all patients diagnosed by certified Alzheimer's Evaluation Centers as having Alzheimer's disease or related disorders. This would involve waiving the two-year waiting period and listing Alzheimer's as a presumptive cause of disability. All Alzheimer's patients would be eligible for all Medicare covered services.
- Expansion of the Medicare benefit package to include an initial evaluation for Alzheimer's disease from certified Alzheimer's Evaluation Centers and development of a plan of care.
- Expansion of the Medicare benefit package to include adult day care services for Alzheimer's patients requiring continuous supervision.
- Removal of restrictions on home health benefits for Alzheimer's patients (e.g. unstable condition, intermittent care, need for skilled nurse or physical therapy services, homebound).
- Expansion of mental health benefits, including counseling for caregivers and raising the limit on covered expenditures.
- Addition of respite care services which would provide a specified number of days (e.g. 30 days

for patients with severe dementia) during the year which could be used by caregivers to spend time away from the Alzheimer's patient. Caregivers would be given the option of taking these in blocks of time (e.g. two weeks twice a year) or on a gradual ongoing basis (e.g. one-half day every week). Respite care could take the form of an attendant in the home during absence of the caregiver or placement in a suitable facility (nursing home or hospital).

2. Discussion

This option places primary emphasis on providing support to caregivers to postpone institutionalization as long as possible. It would provide for the sophisticated assessment of Alzheimer's disease to provide families with the best possible indication of the presence of the disease. Centers would develop plans of care that could be followed by family physicians, thus providing state-of-the-art guidance to physicians providing ongoing management of the patient. It would relieve families of the financial burdens of physician services related to the diagnosis and management of Alzheimer's disease, as well as acute care services required for the treatment of related or nonrelated physical problems.

Adult day care and respite care would reduce stress on caregivers. In some cases this is likely to postpone institutionalization. It would improve the quality of life

for most caregivers. (Lave, 1985)

Its primary disadvantage, other than cost which is not currently estimated, is the involvement of the Medicare program in establishing standards for coverage and payment for a broader array of services -- assessment, adult day care, attendant care, respite care. Similar problems could emerge in defining new standards for expanding home health coverage. Expanding eligibility to patients with Alzheimer's disease and related disorders gives Medicare another diagnosis-specific category of patients (in addition to end-stage renal disease) which may not be the most efficient or equitable way to expand coverage.

B. Improvements in Medicaid

This option would build upon the basic framework of the Medicaid programs to improve coverage for Alzheimer's patients with low incomes. It would not apply to middle income families unless outlays for health and long-term care services impoverished the family.

1. Option 2: Medicaid Expansion

This option would include:

- Coverage of home and community-based services including case management, personal care services, chore services, attendant care, respite care, adult day care, home modification, home technological aids, and financial management services for Alzheimer's patients as a mandatory service under

Medicaid. This benefit would not be contingent on offsetting savings from reduced nursing home care, nor would it be restricted only to those qualifying for nursing home care.

- Expansion of income eligibility up to 300% of the Supplemental Security Income (SSI) individual or couple payment level for Alzheimer's patients.

2. Discussion

This option is also oriented toward improving coverage for Alzheimer's patients in the home and community. It would need to override current Medicaid statute restrictions prohibiting differentiation by diagnosis. Home and community-based services are now available on a limited waiver basis. Not all states have such waivers, and many are limited to certain population groups such as the mentally retarded. Implementation of this provision of the law has been delayed and hindered by administrative mechanisms. Further the benefit is restricted by the necessity of state assurance that the benefit will not add to total Medicaid outlays. As a result, home and community-based services are available only to a small proportion of low-income Alzheimer's patients. This option would automatically make the benefit available to all Medicaid beneficiaries with Alzheimer's disease.

Nursing home coverage is now available for patients with incomes up to 300% of the SSI payment level; the proposal

would extend this income eligibility level to recipients of home and community-based services. An alternative would be to set an intermediate standard such as 200% of the SSI payment level. Expansion of Medicaid eligibility would assure that home and community-based services for Alzheimer's patients were available to all Alzheimer's patients eligible for nursing home benefits. This change would provide some protection for the caregiving spouse against the financial destitution that long-term care could bring.

Again, the major disadvantage of this option is that it would add to the cost of the Medicaid program. Some incentives or standards would need to be developed to assure that services provided were not in excess of legitimate needs. Provisions would need to discourage total substitution of informal care for paid care. For example, a per person dollar cap might need to be set on home and community-based services to assure that they did not exceed the cost of nursing home care. This dollar cap might vary with the degree of disability of the patient. The benefit might draw on the design of the hospice benefit, since states have the option of covering hospice services under Medicaid.

C. Major Long Term Care Reform

Another approach to financing care for Alzheimer's patients would be comprehensive reform of long-term care financing to address institutional care financing as well as services in the home or community. Several major long-term

care financing options have surfaced recently. These options could be redesigned to apply only to Alzheimer's patients -- rather than the proposed extension to all elderly and disabled people.

1. Option 3: Medicare Coverage of Long-term Care

This option has been proposed by two major recent studies. It would add a new part of Medicare covering a comprehensive long-term care benefit package. (Davis and Rowland, 1986; Harvard, 1986) The major features of the option include:

- Covered benefits include nursing home care (both in qualified skilled nursing facilities and intermediate care facilities), expanded home health services (without many of the restrictions in the current Medicare program), and day hospital services.
- Benefits would be subject to a coinsurance charge (such as 10 to 20 percent) and would have a ceiling on out-of-pocket costs.
- Coverage could be mandatory or voluntary, with provisions to prevent adverse risk selection.
- Financing would be through an income-related premium or through a combination of payroll tax revenues, federal general revenues, and premiums.
- Cost control mechanisms would be incorporated

in the form of assessment teams to determine eligibility for benefits and prospective payment of long-term care providers.

- o A direct grant program to public and nonprofit community organizations would provide home help services such as attendant care, personal care services, and chore services.
- o Medicaid long-term care coverage would continue as a residual program for those low-income people not choosing to purchase Medicare coverage.

2. Option 4: Canadian Model of Long-term Care Financing

Rosalie A. Kane and Robert L. Kane have studied universal long-term care benefits in three Canadian provinces (Ontario, Manitoba, and British Columbia) and suggested that a similar approach would be feasible and desirable in the U.S. (Kane and Kane, 1985) The Kanes note that universal long-term care insurance in Canada replaced an earlier system of long-term care for the indigent. While each provincial program is slightly different, the major features of this approach as applied to the U.S. would include:

- o Federal block grants to states for long-term care.
- o State universal long-term care insurance to all individuals regardless of age or income.
- o Benefits based on degree of functional impairment, including nursing home care,

home nursing services, and homemaking services.

- Patients copayments of $10 to $15 daily for nursing home care.
- Payment to nursing homes by level of care (e.g. Level I -- personal care; Level II -- intermediate care; Level III -- psycho-geriatric care; Level IV -- extended care for patients who can not get out of bed) and type of facility. Facilities may be paid on a negotiated per diem rate or a negotiated budget basis.
- Access to services would be determined on the basis of assessment by specified gatekeepers such as physicians, care managers, or home care coordinators.
- Homemaking services would be limited to a fixed number of hours per month or maximum cost not to exceed nursing home care. Home care would be free to the patient.
- Home nursing and homemaking services would be either provided by salaried public employees or purchased from for-profit or nonprofit agencies.

3. Option 5: Governmental Reinsurance of Private Long-Term Care Insurance

This option would set standards on private long-term care insurance as a condition for federal government reinsur-

ance. Reinsurance protection against adverse risk selection or high expenses could be in the form of a stop-loss provision that would protect private plans against losses above a given corridor or could assume coverage once some threshold was passed (e.g. three years of nursing home care or $100,000 per beneficiary).

4. Discussion

The major source of financial burden for the care of Alzheimer's disease is nursing home care. While enabling as many people as possible to continue to function in the home is a desirable objective, it is an unrealistic goal for many Alzheimer's patients -- particularly those in advanced stages of the disease. Therefore, some form of major long-term care financing reform will be required to provide adequate financial protection to families of Alzheimer's disease.

Each of the long term care reform options listed above would address coverage of nursing home care. All options would all provide financing for a broad range of long-term care services, including nursing home care. Coverage would not be conditional on meeting an income eligibility test. Each would require some modest patient financial contributions toward nursing home care.

These options have the advantage of removing the serious financial burdens that Alzheimer's patients and their families bear. They are undoubtedly costly and would require

substantial public budgetary outlays. Sources of revenue would need to be identified to meet these outlays. In addition, all of the options entail establishing mechanisms for assessing patient functional impairment for the purposes of defining eligibility and matching services to patient needs. Each option is likely to improve the available supply of long-term care services and choices among willing providers. However, to prevent abuses, quality control and payment provisions would need to be carefully designed.

Each option would reduce dependence of middle income elderly on Medicaid by reducing the likelihood of spend-down. It would expand service options currently open to older Americans.

Option 5 might induce more private long-term care insurance, and would prevent some abuses in the market by guaranteeing some minimum standards on private coverage. It is still likely to cover only a limited number of those at risk, and private companies could be expected to continue their current efforts to attract relatively low-risk individuals.

D. Payment and Service Delivery Reform

Another set of policy options could be restricted to improving payment methods and incentives for service delivery reform in the current Medicare and Medicaid programs. The two main options are expanding capitated payment of acute and long-term care services through Social Health Maintenance

Organizations (SHMOs) or other capitated arrangements and reform of nursing home payment to address the substantial care requirements of Alzheimer's patients.

1. Option 6: SHMOs/Life Care Communities/Capitation

Currently, Medicare is testing the Social Health Maintenance Organization concept on a demonstration basis. Under this concept, SHMOs are paid a fixed capitation rate for a defined enrolled population, and in turn provide an array of long-term care services including nursing home, home health, homemaker, respite and other services. At least initially, SHMOs will limit their financial risk with both a maximum per person payment for long-term care services and copayments. If this proves successful, one option would be to institute this option on a nationwide basis.

Life care communities might also be candidates to receive capitated payments from Medicare and/or Medicaid. These organizations assume financial risk for acute and long-term care services not covered by Medicare, as well as providing housing for nonimpaired individuals. There is some evidence that the services of such organizations including on-site nursing care, part-time physician care, and nursing home beds reduce reliance on hospital care. A capitated rate from Medicare could permit these savings if realized to be channeled into a broader range of care services.

The main advantage of a capitated approach is that it may save money by reducing inappropriate use of hospital,

nursing home, and other medical services. Managed care offers patients more of the services they want and need to remain in the community and at home. It avoids restrictions in Medicare and Medicaid that are not conducive to providing the patient with appropriate services. As yet, however, the extent of patient interest and the feasibility of cost savings have not been demonstrated.

2. Option 7: RUGS and Nursing Home Payment Reform

Another option would be to change the way that nursing homes are paid under the Medicaid program. Currently, states have a great deal of latitude in establishing nursing home payment methods. A few states, such as Maryland, use graduated levels of patient care requirements as a basis for payment. Others use uniform per diem payment rates that discourage nursing homes from taking complicated care patients such as Alzheimer's patients.

A new patient classification system, RUGS-II, uses an Activities of Daily Living index and distinguishes between dementia patients who need intermittent and constant supervision. Payment is in accordance with the amount of care required.

This option is not exclusive of other options and could be a part of any long-term care reform package.

E. Targeted Programs

The above options are financing options that emphasize a public insurance or entitlement approach to long-term

care. Another approach is creation of a categorical program for care of Alzheimer's patients that would target funds on selected supportive activities -- rather than financing care directly.

1. Option 8: Evaluation Centers, Training, Research, Coordination, Clearinghouse, Hot Line, Support Groups, Voluntary Service Exchange Banks

This option would authorize specific sums of money to be appropriated annually to support the following activities:

- o Evaluation: One or more centers would be established in each State to do state-of-the-art diagnosis and plan of care for individuals suspected of having Alzheimer's disease or a related disorder. The centers would provide services and would not necessarily correspond with the current Alzheimer's centers that conduct research.
- o Training: Fellowships to enable geriatric training programs to have sufficient experience dealing with Alzheimer's disease would be established for physicians and nurses.
- o Research: The number of Alzheimer's research centers funded through NIA would be increased from 10 to 20 centers.
- o Coordination: States would apply for up to 10 grants to improve the coordination of services for Alzheimer's patients and develop improved

public education programs on diagnosis and treatment of the disease.

- o Clearinghouse: A national clearinghouse for Alzheimer's disease and treatment would be established to provide current information on research and treatment progress to states, providers of care, and patients and families. The clearinghouse would provide a toll free hot line number to provide information and counseling to families dealing with patients.
- o Support Groups/Service Exchange: Funds would be used to organize Alzheimer's support groups. Funds would also support the development of volunteer service exchange programs to provide respite services to caregivers.

2. Discussion

This option is relatively low cost (probably less than $100 million) and controllable since funds would be appropriated annually through the normal budgetary process. It would assure the availability of qualified professionals and centers to provide state-of-the-art knowledge, diagnosis, and care plans. It could complement other options by assuring the availability of qualified personnel and contributing to the development of quality standards.

F. Tax Subsidies

Another policy approach is to provide tax subsidies to

provide incentives to individuals to finance long-term care privately. Tax subsidies result in foregone tax revenues and contribute to the federal budgetary deficit in the same way as direct federal budgetary outlays. They should be analyzed like any other governmental expenditure program. Two types of tax subsidies warrant consideration: tax subsidies to encourage private savings for long-term care through individual retirement accounts (IRAs) restricted to the payment of long-term care expenes and tax subsidies to encourage family members to provide or contribute financially to long-term care of Alzheimer's patients.

1. Option 9: Individual Retirement Accounts

Currently, an individual may set aside $2,000 annually in an IRA and exempt this contribution from taxable income. Taxes are deferred until savings are withdrawn after age 59. This results in substantial benefits to the individual (and substantial tax loss to the Federal treasury) because taxes are deferred until some point in the future when marginal tax rates in the retirement years are presumably lower. IRA savings may be used for any purpose. To encourage the targeting of IRA savings on long-term care, the following provisions might be adopted:

- o IRA savings withdrawn and used for health or long-term care savings after age 59 could be treated as exempt from income taxation. IRA savings withdrawn and used for other purposes would be counted as at

present as a form of taxable income.

- The current provision that savings must be withdrawn by age 70 1/2 could be extended to age 75 when individuals are more likely to require long-term care.
- Restrict withdrawals from the IRA for the sole purpose of paying long-term care expenses.

2. Discussion

Option 9 has the advantage of encouraging individuals to save for future long-term care expenses. It would give families the flexibility to use savings for those services that they feel best meet their needs. It encourages the private sector to develop and market more services.

Experience with IRAs suggest that they do little to increase total savings -- but rather shift savings from one form to another. In 1984 15.4 million taxpayers contributed to IRAs. These were predominantly higher income individuals. Option 9 is likely to result in large tax breaks to higher income individuals and to provide little assistance to lower income individuals in greater need of long-term care. These options do not pool risk across individuals and provide no assurance that savings will be adequate to meet long-term care needs.

3. Option 10: Tax Subsidies to Families Contributing to the Care of Alzheimer's Patients

Another approach would be to provide subsidies to

families contributing either in kind or financially to the care of Alzheimer's patients. Two provisions might be considered:

- An additional tax exemption for dependents with Alzheimer's disease.
- Permit adult children of Alzheimer's patients to claim an itemized deduction (or exemption from income) for financial contributions toward medical equipment, drugs, home hedalth, personal and nursing home care. This would not be conditional on demonstrating that the parent was a dependent or that the adult child contributed more than 50 percent toward the care of the parent.

4. Discussion

This option would provide families with modest financial rewards for providing care to Alzheimer's patients. It offers some means to purchase respite and other services, and may offset some expenditures that would otherwise eventually be paid by the Medicaid program. It is an expansion beyond the current dependent care tax credit deduction for disabled elderly. This tax credit is set at 20 to 30 percent of expenditures up to a maximum of $2,400.

Its major disadvantages are that it results in foregone tax revenues, benefits higher income individuals more than lower income individuals, and provides only minimal help to families in greatest need. Unlike direct expenditure

programs, tax subsidies do not provide any opportunity for controlling the price or assuring the quality of long-term care services.

III. Summary

Providing and paying for the care of people afflicted with Alzheimer's disease and related disorders has become an immense unsolved social problem. It tests the very mettle of the nation's commitment to social justice and to ensuring individual dignity. No other illness carries the same emotional burden, extraordinary cost of care, loss of human dignity, and dearth of services most needed by patients and their families. No American is immune from the threat of this tragedy in his or her own family. Continued inaction undermines the image of this nation as a caring and compassionate society. All of us have a common stake in assuring a better future for Alzheimer's patients and their families.

Decisions regarding long-term care policy reform are inevitably contingent upon costs. Reluctance to incur high costs has been and will continue to be a deterrent to policy action. There is a need for more information about the costs of alternative options, about which services work best and are most needed by families, and which are most cost-effective. Little is known about the possibility of offsetting savings to Medicaid or to the health system through a well-conceived and well-managed system of care for dementia. The research and analysis necessary to obtain this information

should be pursued aggressively.

The policy options set forth in this paper run the gamut from modest initiatives to comprehensive reforms and from direct governmental outlays to governmental subsidies for private activities. Each has its own advantages and disadvantages. This list of options should be refined and their merits more closely scrutinized.

Policy officials need to come to some resolution regarding the basic strategy for action -- incremental improvement in existing programs as budgetary resources permit or a sweeping reform replacing current programs. Even a modest first phase building the necessary infrastructure would be preferable to continued inaction.

The current system causes emotional and financial devastation to millions of Americans. It is hoped that the policy options set forth in this paper will focus debate on feasible and desirable policy actions to relieve these burdens.

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